

# An Improved Picture of HIV Name-Based Reporting

Name-based reporting is the system all states use for AIDS diagnoses. Most states also use name-based reporting for HIV cases (HIV is the virus that causes AIDS). Vermont, however, is one of four remaining states that use a code-based, rather than a name-based system for reporting HIV diagnoses.

The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) are strongly recommending that Vermont and the other remaining states adopt a name-based reporting system for HIV diagnoses.

The CDC and HRSA provide a majority of the funding for Vermont's HIV/AIDS Prevention and Services programs. These agencies calculate the amount of federal funding by using a formula that includes the number of HIV cases as reported by the states. The CDC and HRSA have made it clear that a name-based reporting system is the only acceptable source of these figures. If Vermont does not adopt this system for HIV diagnosis, we risk the loss of full federal funding.

To ensure full funding, Vermont should begin the process to change its reporting system in 2007.

## What is Name-Based Reporting?

- Currently, in name-based reporting of AIDS cases, patient names are forwarded to the Health Department by health care providers when AIDS is diagnosed.
- With the current system for AIDS diagnoses, patient names are kept secure and confidential at the state's Health Department. No patient names are forwarded to the federal government. Instead, the Health Department generates an alphanumeric code to accompany data forwarded to federal health agencies.
- Name-based reporting for HIV will be similar to name-based reporting for AIDS.
- Names of patients with HIV or AIDS will not be sent to any federal agency.

## 22 Years of Secure and Confidential Records

- Vermont has used name-based reporting for AIDS case diagnosis for 22 years.
- Electronic records are stored at the Health Department in a non-networked computer located in a secure, locked room. The computer is password-protected.
- Paper forms are also secured. After the data are entered, the part of the form with names and addresses is removed and shredded. The remaining form is stored in a locked filing cabinet in a locked room.
- Only a very limited number of department staff have access to the records. In addition, all employees of the Health Department must undergo records privacy training and sign confidentiality statements.
- Vermont reports confirmed cases of AIDS to the CDC, but does not report an individual's name or health care provider information, such as physician names or telephone numbers.



**DEPARTMENT  
OF HEALTH**

108 Cherry Street  
PO Box 70  
Burlington, VT  
05402-0070  
[healthvermont.gov](http://healthvermont.gov)

## What Won't Change –

### **Strict Confidentiality Rules**

Individual AIDS and HIV data records are not shared with any other programs. This will not change with name-based HIV case reporting.

### **Anonymous Testing Will Still Be Available**

- Anonymous HIV testing will remain anonymous.
- Providers of anonymous testing would not ask for a name when giving a positive test result. Just as now, the provider would report an HIV positive test to the state – without a name attached.
- People who test positive at an anonymous counseling and testing site are encouraged to seek medical assessment with an HIV specialty care provider such as the Comprehensive Care Clinics. People who enter medical care for evaluation and possible treatment of HIV infection are tested in the confidential medical setting to confirm an HIV positive test result.
- Only when HIV diagnoses are made in the confidential medical setting will patient names be forwarded to the Vermont Department of Health.

### **Access to Comprehensive, High Quality Care**

- Through voluntary anonymous and confidential HIV testing, people discover their HIV status and receive counseling to help determine the risks for HIV transmission, and to develop plans for reducing their risk.
- People who test positive for HIV are encouraged to enter the HIV care system in order to benefit from ongoing health assessment, care and treatment – including mental health and substance abuse treatment services; treatment for HIV infection; prevention, prophylaxis and treatment of opportunistic and other infections.

### **Next Steps**

- The switch to a name-based reporting system will require changes to state law by the legislature. The next legislative session will begin in January 2007.
- Between now and the start of the session, the Health Department must submit a transition plan to the CDC, and publicly commit to making this change.
- Department staff will continue to work cooperatively with organizations, communities, and individuals around the state in developing the plan, and to address any concerns Vermonters may have.

### **Benefits of Making this Change**

- Under the current surveillance system for HIV cases it is difficult to evaluate the accuracy of Vermont's HIV reporting.
- Name-based reporting is expected to improve Vermont's ability to quantify and report the number of HIV positive individuals accurately and without duplication, while continuing to assure confidentiality.
- Improved data will better enable the Health Department to describe the HIV/AIDS epidemic in Vermont, and guide prevention and care services for Vermonters.
- Adopting the name-based standard will help ensure full federal funding for HIV prevention and services programs.